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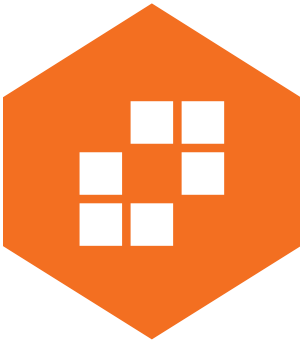
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An Investigation of the Methods Used by Designers to Engage with Users that Have Specific, Critical Additional Needs (SCAN)

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Abstract: Despite the need for increased engagement of differently-abled users throughout the design process, little attention has been placed on the inclusivity of requirements and data gathering methods. This shortcoming can result in inappropriate and non-inclusive products. The training of designers may not provide sufficient opportunities to develop the skills, insight and expertise designers require to work with SCAN users. Although some designers in this sector may have an intimate knowledge of disability, it is hypothesized that the majority of designers are ill-prepared to work with SCAN users. Three focus groups, augmented by telephone interviews, were conducted to explore the methods used, experiences, and attitudes of designers when working with SCAN users in order to understand engagement methods and difficulties they encountered. This paper presents the gap in knowledge, provides insight into the experiences of designers working with SCAN users, and outlines the way in which this gap will be filled.

Keywords: Inclusive Design, Critical Needs, User Research

Introduction

This paper provides a summary of the key findings from the first stage of a three stage study which seeks to understand how designers make use of user centred design and evaluation methods when working with those that have Specific, Critical, Additional Needs (SCAN). The aim is to produce guidelines that assist designers in making reasoned methodological choices in relation to the user groups they are designing for. Focus groups and Skype conversations were conducted with a purposive sample of product designers (drawn from the United Kingdom and the United States of America) to elicit information on the way in which they addressed SCAN and non-SCAN users in the design and evaluation process. The paper includes a review of the study and its findings. It will also examine how the information gathered from this stage will inform the next stage of the research.

For the purposes of this research, SCAN users have been defined as individuals that have specific, critical needs which need to be met in order for them to maintain their quality of life, but which are additional to that of common everyday critical needs. An example of a Specific, Critical, Additional Need, is that of a person who cannot feed themselves without assistance.

The overall aim of the research is to produce guidelines to assist designers in the selection of the most appropriate research methods to support user centred design and evaluation at all stages of the process (as defined in ISO standard 9241-210:2010-see figure 1 below).

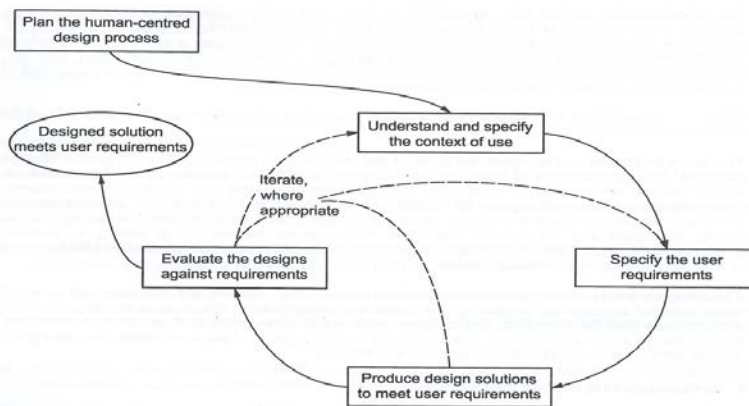


Figure 1: Interdependence of Human-centred Design Activities (ISO 9241-210:2010 (E))

Source(s): International Standards Organisation (ISO) 2010

This should enable designers to work more effectively with SCAN and disabled users in particular. Given that the adoption of user centred design approaches require designers to work for, in partnership with, and led by users; development of non discriminatory, appropriate methods and behaviours are essential. These would then provide better opportunities for users to contribute to research. Additionally, this may also assist with better sampling (e.g. of users on citizen panels or focus groups) in that it would not be restricted because of lack of appropriate tools and knowledge to communicate effectively and in depth with these users. The development of such methods is an essential building block in developing products and services to meet the needs of this group.

A literature review not only found little published work in this area, but also demonstrated need for this work, for example Roberts and Fels (2005,489) comment that “Many of these methods are not designed to include users with disabilities, legislation and good design practice should provide incentives for researchers in this field to consider more inclusive methodologies.”

With the advent of legislation such as the Equality Act 2010 (in the UK), it is unlawful to treat a person with a protected characteristic (for example an individual with a disability) less favourably than another. Other factors also require a fuller understanding and a rethinking of the needs of SCAN users, these include the potential size of the assistive devices and technology market (reported as “...£1.46 billion for 2008...”, Key Note Market Report 2006), new models of disability which see it is a social concept (e.g., the Social Model of Disability, Scullion, 2010) and ethical drivers in which most people perceive discrimination inappropriate (Griffin, 1993).

When combined with evidence collected in this study i.e. a participant remarked “...adequate ethical guidance for designers is pretty important really...” this indicates that designers could benefit from additional guidance in developing effective relationships with SCAN (and other) users.

An output from the completion of this research will be guidelines that can be used to aid in understanding:

- The context of use
- User requirements
- Evaluating iterative designs
- Informing iterative designs against requirements i.e. any design stage which involves end users

Designer friendly material in this territory has already been developed in the form of websites such as the Inclusive Design Toolkit (www.inclusivedesigntoolkit.com), Designing with people (www.designingwithpeople.org), University of Cambridge Inclusive Design Website (www.eng.cam.ac.uk/inclusivedesign/index.php), The Methods Lab-User Research for Design

(www.education.edean.org/pdf/Tool039.pdf), Helen Hamlyn Centre for Design (www.hhc.rca.ac.uk/4577/all/1/videos.aspx) and IDEO (www.ideo.com/about/). Material is presented in a way that is appealing and usable to designers in so far as it is visual, clean and uncluttered, using short paragraphs of text interspersed with appropriate images and other media (as highlighted in Table 1). Thereby following the comments of two participants in this study who state that "... you should use audio visual information rather than just a bunch of words [because] they...won't ... look at them..."

Table 1: Summary of the Features Employed by Each of the Resources

<i>Resource</i>	<i>Images/ Diagrams & Text combined</i>	<i>Case Studies</i>	<i>Tables/ Data</i>	<i>Video</i>	<i>Use of Subheadings</i>	<i>Navigation Aids</i>	<i>Links to other Resources & References</i>
<i>Inclusive Design Toolkit</i>	✓	✓	✓		✓	✓	✓
<i>Designing with people</i>	✓	✓	×	✓	✓	✓	✓
<i>University of Cambridge Inclusive Design Website</i>	✓	✓	✓	×	✓	✓	✓
<i>The Methods Lab-User Research for Design</i>	✓	×	×	×	✓	✓	✓
<i>Helen Hamlyn Centre for Design</i>	✓	✓	×	✓	✓	✓	✓
<i>IDEO</i>	✓	✓	×	✓	✓	✓	✓

The research has significant overlaps with the i~design 3 project, the aims of which were to "make the practice of inclusive design more effective by giving designers more accurate, relevant and up-to-date data on capability in the population" (i~design 3). This led to the development of some of the online resources referenced above. Whilst it is acknowledged that these make an extremely valuable, useful and relevant contribution to inclusive design knowledge these focus on the process of inclusive design and its success (e.g. through the Exclusion Calculator and Demand Assessment Grid) rather than on the selection of the most appropriate method used to support inclusive design with a specific group of end users.

The project website www.designingwithpeople.org features information on available methods but lacks specific information on how these methods can be used with SCAN users and their suitability for use with different populations. Instead, the emphasis has been on what stage of the project each method is suitable for.

Additionally, further resources such as the British Standards Institution BS 7000-6 (2005) only consider method selection fleetingly i.e. stating that "Due consideration should be given to customers and end users at each stage of development, and care taken to employ the most appropriate methods, for example, written questionnaires are not easily accessible to those with visual or cognitive impairments."

Therefore, the specific aim of this project is to produce guidance to assist designers in the selection of the most appropriate methods to support user centred design and evaluation when working with participants with SCAN thus providing a solution to the knowledge gap outlined

above. This paper reports on the initial stage of the research, the specific objectives of which were to:

- Investigate designers' experiences of working with SCAN users.
- Investigate how users with SCAN (including their carers) and other user groups are treated as part of design and evaluation processes.
- Identify key themes and recommendations that will form the basis of guidelines to assist designers to make reasoned methodological choices when working with SCAN participants (and their carers where appropriate).

Methodology

Focus groups and Skype conversations (for those not able to attend the focus groups) were used to enable participants to discuss issues related to the way in which they worked with SCAN and non-SCAN users during the design and evaluation process. The reason for the selection of the focus group method was that it enabled participants to share experiences, observations, thoughts and feelings (adapted from Kuhn 2000). Furthermore, the focus group method was appropriate because it facilitated knowledge sharing and exchange. Additionally the focus group:

- allowed people to air their views in a natural conversational way;
- enabled a wide variety of perspectives to be sampled quickly;
- did not require special equipment;
- were comparatively easy to conduct (adapted from Maguire 2003,73).

It was important to create an atmosphere where designers felt at ease, so they could share what may be challenging, difficult and in some cases highly emotional experiences of working with SCAN users. The focus group sessions lasted between 45 and 90 minutes. A template was drawn up to enable structured and purposive discussion. This was distributed to all participants in advance. The topics covered were:

- General introduction (this enabled participants to introduce themselves and outline their background; this was used as an ice breaker)
- The involvement of the user in the design process
- Design methods used by participants
- Involvement of SCAN users in the design process
- The designer in the design process
- Suggested guidelines
- Format of guidelines



Figure 2: A Focus Group in Progress

Source(s): Sherriff 2012

The focus groups were conducted in a usability laboratory with a one-way mirror which allowed the researcher to see the focus groups and the facilitator. The focus groups were video and audio recorded for analysis purposes with some notes being taken of important points to aid in the analysis. A facilitator introduced the questions for discussion and made sure that all participants had an equal opportunity to contribute and encouraged discussion of items that arose naturally during the course of conversation without prompting. The telephone conversations were conducted via Skype using a similar process.

The facilitator was also used to:

- reduce experimenter bias;
- ensure that the discussion was relevant to the overall topic;
- prevent the discussion being dominated by one single or a group of participants.

15 participants took part:

- The control group consisted of 4 male designers, with no experience of working with SCAN users.
- Two focus groups consisting of a total of 7 designers with experience of working with SCAN users formed the experimental groups (6 male and 1 female).
- In addition, to the focus groups 4 Skype conversations were held with 2 US (female) and 2 UK (male) designers, who had experience of working with SCAN users.

Participants were selected using purposive sampling. Additionally, chain or snowball sampling was used to widen the pool of potential participants based on the recommendations of initial participants, friendship groups and industrial design staff at Coventry University. The majority of the participants who took part were not known to each other. However, those in the second SCAN focus group all worked at the Bath Institute of Medical Engineering and two of the participants in the first SCAN focus group were professionally acquainted.

Analysis

A thematic analysis was conducted to extract key themes from the data. This could be described as a method for identifying, analysing, and reporting patterns (themes) within data... [that] minimally organises and describes your data set in (rich) detail ...however, it also often goes further than this, and interprets various aspects of the research topic (adapted from Braun and Clarke, 2006:6, Boyatzis, 1998). This was achieved by the researcher reading and re-reading the transcripts of the

focus groups and telephone conversations to both understand and identify emergent themes. Once the themes had been identified the relevant information was matched with and placed in the relevant theme, colour coded and placed in a relevant folder. A manual approach to data analysis was adopted because this allowed greater immersion and understanding of the data; the action of physically moving transcripts into a category and subsequently a folder enabled the researcher to develop a picture of the relative importance of different themes and chart his progress in the data analysis.

Results

Seven distinct themes emerged, these were:

- 1) Differences in design practice between UK and US designers
- 2) Use of intermediaries in the design and evaluation process
- 3) The nature of working with SCAN participants
- 4) Ethical issues when working with SCAN participants
- 5) Use of language
- 6) The maintenance of professional boundaries
- 7) Engaging with users

This section provides an overview of issues identified in each theme.

Differences in Design Practice between UK and US Designers

A notable difference was found between the designers from the two countries. The US participants were more inclined to embrace and to conduct work directly with SCAN users, evidence for this assertion can be found when one participant states "...we actually, for the most part we did it on a very personal level, face to face..." and "...in the actual designing process they were involved from the beginning when I started to talk with them and get their input on what direction for my project to take..." Whereas UK participants admitted that there was room for improvement in their practice "...I would argue... with users we could improve, it's poor if I'm being honest..."

The differences may be explained by:

- The fact that both US participants have disabilities which may have made them personally more sensitive to the need to work more closely with users and the emphasis placed on this in their training.
- Legislative issues relating to the Americans with Disabilities Act which was introduced in 1990, 5 years prior to the UK government providing comparable legislation (Disability Discrimination Act 1995).
- Wider socio cultural issues around disability

No other differences in ways of working with SCAN users were found in this study.

Use of Intermediaries in the Design and Evaluation Process

It was found that 87% of the sample made use of some form of intermediary as well as, or in place of the end user. This approach to working with SCAN users has been recognised (as outlined by Cogher *op.cit*) but does have its disadvantages as outlined by Blow (2008). It is clear from those that took part in the study that guidance on the appropriate use of carers/support workers is needed. For example, designers commented that one should "be very aware...of the user and the carer, they all have different requirements" and in some cases, the requirements of the primary and secondary users i.e. the user and the carer are not the same "may well be areas that don't overlap and maybe

even conflicting requirements.” However, the position of this research is that both the user and carer should be consulted because carers notice “things that the person themselves don’t notice.”

Additional guidance is required for designers who have to use intermediaries, to ensure that:

- 1) The requirements and feelings of the SCAN user are given precedence
- 2) The feelings of the SCAN user are not misinterpreted
- 3) The SCAN user’s involvement is not tokenistic.

Unfortunately, the reliance on intermediaries may also mean that designers do not have the methods or skills needed to work with SCAN users, with an over reliance on proxies taking away the agency of the SCAN users and leading to positions where designers never come into contact with end users.

The Nature of Working with SCAN Participants

Health issues and the nature of disability were raised as barriers to working with SCAN users by the participants. Issues included:

- Involvement of SCAN users who may be more prone to illness and therefore not be able to participate fully in sessions, or who may have to miss scheduled sessions. This is especially problematic in cases where design has to be undertaken in a set time frame.
- Awareness of design teams to not pass on any illnesses to the SCAN users who may be more susceptible to infections than the general population.
- Lack of acceptance and understanding of the onset and nature of Specific, Critical, Additional Needs by the participants or members of their family, especially in relation to the onset of degenerative disease.

Ethical Issues When Working with SCAN Participants

Ethical issues were raised by participants in all groups as they felt it limited the level of testing that can be undertaken, and thus reduced the amount of feedback they could gather. However, the study indicates that designers understand its importance, with one participant stating that “adequate ethical guidance for designers is pretty important really” The need for ethical guidance is particularly acute within the private sector, as one participant highlighted guidance in this area for private sector businesses is not available. Young designers or those moving into the sector, in particular, need more guidance. Although undergraduate courses do cover some ethical issues, this training may not be detailed enough or relate specifically to the design and evaluation of medical/assistive technology products. This will become a greater issue as more products, with greater levels of sophistication enter the market (for example adaptive technologies which monitor and respond to changes in user needs).

The question of ethics in relation to design practice is one which needs further exploration in terms of:

- method and experience of user engagement;
- the need to develop a model of ethical practice;
- responsibility;
- duty of care and;
- liability which does not stifle design creativity and innovation.

Use of Language

It was highlighted by a significant minority (27%) that designers need to be careful of the language they use when working with SCAN users because this can be problematic as stated by a participant “but if you then inadvertently, in a particular context start saying carers, instead of care giver, in some circles you’d be in trouble for that ...but sometimes you won’t.” Given this, it was seen as advisable to check with all user groups and stakeholders at the outset in relation to what terminology was appropriate and how they defined themselves e.g. disabled person, wheelchair user, deaf, hearing impaired, blind, sight impaired etc. Although this might be seen as a relatively minor consideration, language is an important factor to consider because according to one participant “you want to get the best interaction and you want people to be engaged.” The way in which language is used should be considered across the whole design team and the design and marketing process, not just in one-to-one interactions as it defines the culture and philosophy of the design team; for example stressing inclusivity or universal design as opposed to designing for those with certain disabilities.

The Maintenance of Professional Boundaries

A significant minority (27%) raised issues around professionalism and the need to maintain professional boundaries. The relationship between designers and end users has not been largely explored in the literature. In most cases, the relationship is bounded and of short duration, for example when a representative end user is invited to a design clinic to evaluate a concept or product design. However, with more complex designs e.g. bespoke designs, service designs, or designing for those with complex needs, the design team may have deep and prolonged contact with end users, e.g. through the use of co-design, participatory and ethnographic methods. This may have unintended consequences, in so far as users may feel that the design team’s interest will be sustained after the design work has been completed and that they can apply their expertise to other problem areas. A code of practice and contract for both designers and participants is required which makes the nature and level of the interaction explicit.

Engaging with Users

Applying Arnstein’s ladder of citizen participation (Arnstein, 1969-see figure 3 below) to an analysis of the methods used to engage with SCAN users, the majority of those questioned (73%) used methods low on the participatory scale, especially when designing generic disability products, with a participant stating “I think ...involvement of the user is poor ...but it’s difficult” i.e. at manipulation, therapy, information and consultation levels only. One designer commented that this was due to “...the type of products that [the designers]... work with ...it can be difficult.” The remaining 27% worked on more bespoke designs which required a greater level of interaction with end users. This issue could be addressed by ensuring that the guidelines include information on a wide variety of methods and explain the benefits of using methods that fully engage the user in the process.

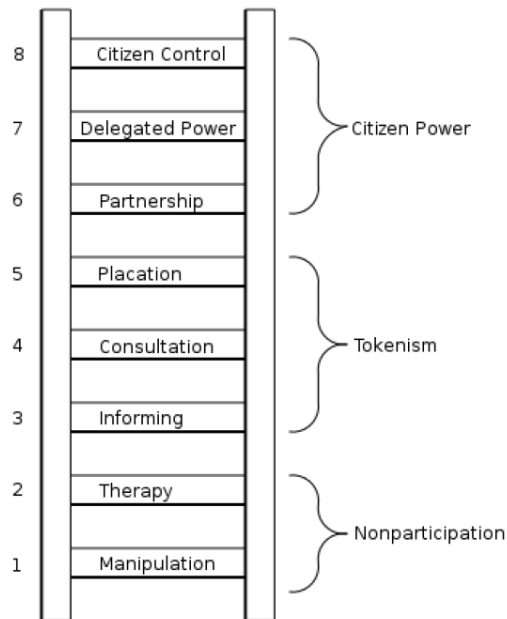


Figure 3: Arnstein's (1969) Ladder of Citizen Participation
Source(s): Herbst 2012

Format of the Guidelines

Table 2 (on the next page) outlines participant choices and the rationale provided for the format of a new set of guidelines to assist designers in the selection of the most appropriate way of working with SCAN users.

Table 2: Guidelines for Designing for SCAN Users

Format	Rationale	Frequency
<i>Website</i>	A website was seen as having potentially the widest impact, as it can: <ul style="list-style-type: none"> • reach the largest number of designers • be a fast means of disseminating research • include multimedia content (e.g. PDF,MP3 and PowerPoint) with a balance of different media • be linked to other resources • be updated frequently • be relatively easy to create and maintain • be accessible and interactive • encourage discussion and knowledge sharing • be a widely used format • be low cost • be accessed by a worldwide audience 	13
<i>Facebook or LinkedIn</i>	<ul style="list-style-type: none"> • could provide a gateway to the guidelines as “... <i>what you’re doing is highly searchable ...and would really get your information out very, very quickly...</i>” • would reach a large population • may reduce the amount of time spent looking for relevant information 	3
<i>PDF, PowerPoint, or Audio</i>	<ul style="list-style-type: none"> • would be accessible to the widest possible population • easy to share and compact 	2
<i>Booklet</i>	<ul style="list-style-type: none"> • accessible • inexpensive to produce • could be made available through a website • could be suitable for those with a preference for a hard copy 	3
<i>Workshops and Academic Courses</i>	<ul style="list-style-type: none"> • useful to talk with and listen to somebody who has a disability • may help a designer feel engaged, involved and part of a design effort 	1
<i>Exhibitions and Tradeshows</i>	useful way of targeting the proposed audience	1
<i>DVD/Video</i>	useful for a designer who cannot gain practical experience of working with an end user	1
<i>YouTube</i>	increasingly popular as an educational tool	1

Discussion

The focus groups confirmed the findings from the literature review in so far as participants felt that there was little information which could help them in the selection of appropriate methods when working with SCAN users. Roberts and Fels (2005) state “Many of these methods are not designed to include users with disabilities. Legislation and good design practice should provide incentives for researchers in this field to consider more inclusive methodologies”. The most popular methods included interviews and direct observation which require a high level of engagement with the end user. The use of such methods has been recommended by ISO/TR 16982:2002 (E) Ergonomics of Human System Interaction-Usability Methods supporting Human-Centred Design (Technical Report) when working with such users.

The use of intermediaries was common practice, as Cogher (2005) states “in the implementation of consultation and involvement where there is a language or communication difficulty, a support worker or family member takes responsibility for interpreting what an individual wants or needs.” However, a disadvantage of this approach is as stated by Blow *op. cit* it “ultimately relies on a shared understanding between two people.” The problems with the use of advocates or intermediaries have been previously addressed, e.g. Concannon (2005) outlined that

“communication is a two-way process but one where reception may be as difficult as expression. If an advocate is included, having another person involved in the process is in itself filled with potential challenges. It is not only understanding what is said that is the problem, but also the hinterland that lies behind it.”

Although a tendency was noted for more experienced designers to use more methods, no firm conclusions could be drawn from this. Additionally, only one participant stated that the methods he used were dependent on the user’s ability. This assertion is reminiscent of Blow *op.cit* who states that “as levels of ability differ from person to person, so must the ways in which research is adapted to meet individuals’ needs.”

Conclusions

As a group, the designers had previously used a wide variety of methods to engage with users (such as structured observation, listening, empathic modelling, intermediaries and role play), but not formal interviews. They also felt that carers could offer useful additional insight into a user’s condition and where required, validate (confirm) information already given by users. This could be useful in cases (for example dementia or communication difficulties) where the SCAN user has such needs which may mean they present unclear or unusual requirements. The group indicated that they felt design for non-SCAN users was easier because there is less variation in requirements. None of the participants thought that working with SCAN users would make a difference to their practice.

It was interesting to note that some participants felt “just because you have a very specific need... you shouldn’t have to have a certain product... you should be able to choose the one that you want and it’s an emotional choice.” However, this does not detract from the need to understand SCAN users who may wish to use mainstream products. Indeed, the onus is on designers to find ways of understanding their needs and requirements and ensuring that these are fulfilled in mainstream products. This necessitates the development of more inclusive methods and practices by designers.

Future Work

As a result of the high level of intermediaries used by the sample, the next stage of the research will be modified to include interviews with carers, users and healthcare professionals (approximately 10 carers, 5 healthcare professionals and 15 SCAN users) to see how this process can be facilitated. Although a neutral stance is taken by the research regarding the use of intermediaries, research will be undertaken to determine how tokenism and misrepresentation of users can be avoided (e.g. through observations of the SCAN user and empathic techniques which enable the designer to understand communication intentions i.e. how they indicate agreement). It may then be possible for the designer to know when the user is showing satisfaction or dissatisfaction with decisions and changes that have been made or statements made by intermediaries (adapted from Blow *op.cit*). These interviews should provide an insight into how users, their carers and healthcare professionals are involved in design and evaluation processes. Participants will also be given the opportunity to provide advice to designers on how to approach working with SCAN users.

The information from all stages of the research will be used to produce draft guidelines to assist designers working with SCAN users in particular. The guidelines will include information on method selection, professionalism and ethical issues (as raised in the first set of interviews). In the final stage of the research the guidelines will be validated by a panel of expert users; both designers and SCAN users, prior to the development of the final guidelines.

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